QAUJIGIARTIIT

ARCTIC HEALTH RESEARCH NETWORK - NUNAVUT

2007-08 FINAL REPORT

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Introduction

Qaujigiartiit/Arctic Health Research Network - Nunavut

The Arctic Health Research Network is the first Canadian tri-territorial health research network linking northern regions. The network includes health research centers based in the Yukon, Northwest Territories and Nunavut. To work towards its mandate to improve health outcomes through research, this network is and must be a community driven, northern lead, health and wellness research network that facilitates the identification of health research priorities in the three territories.

> *The vision for the network includes participation in health research that values both traditional knowledge and western sciences and to address health concerns, create healthy environments, and improve the health of persons in the three territories. It ensures best practices in health research through participation in health research activities, sharing of findings, training of health researchers, and knowledge translation to ensure transfer of findings to policy, practice and community programming.*

The goal of Qaujigiartiit/AHRN-NU is to enable health research to be conducted locally, by northerners, and with communities in a supportive, safe, culturally-sensitive and ethical environment, as well as promote the inclusion of both traditional knowledge and western sciences in addressing health concerns, creating healthy environments, and improving the health of Nunavummiut.



The Arctic Health Research Network in each territory works with communities to develop health research priorities to share with researchers coming North, as well as works with Northern training programs to facilitate northerner participation in the development, design and delivery of health research projects that can be run in communities by community members.

Representatives from Nunavut Tunngavik Inc., the Nunavut Association of Municipalities, the Nunavut Research Institute and the Dept. of Health and Social Services, youth and community members are currently involved in the initiative and are members of the Board of Directors._

Funding

For the initiatives described in this report, the Qaujigiartiit/Arctic Health Research Network received funding from

- the Tri-Territorial Health Access Fund
- the Canadian Institutes for Health Research Team Grant (University of Toronto)
- the Isaksimagit Inuusirmi Katujjiqatigit Embrace Life Council

We are grateful for the financial support contributed by these organizations, without which the Arctic Health Research Network would not be able to operate.

Board of Directors

The Qaujigiartiit/Arctic Health Research Network - Nunavut is guided by a board of directors comprised of the following 6 members:

- Nunavut Association of Municipalities, represented by Lynda Gunn
- Nunavut Tunngavik Incorporated, represented by Virginia Qulaut Lloyd and Laakuluk Williamson
- Nunavut Dept. of Heath and Social Services, represented by Andrew Tagak Sr.
- Nunavut Research Institute, represented by Carrie Spavor and Jennifer Wilman
- Sarah Jancke, Youth Representative
- Jodi Durdle, Community Member Representative

The board of directors met 3 times in 2007-08 in Iqaluit, including an AGM in June 2007. The board of directors has been very involved in the work of Qaujigiartiit/AHRN-NU and it is a pleasure to work together on community health and health research initiatives.

Vision for 2007-08

The vision for the Nunavut network site was to build our connections with community members; provide opportunities for training in health research-related fields; create an environment of open learning and sharing in terms of community health and research knowledge; conduct a review of community ethical guidelines for health research and collect community input on health research ethics protocols; examine health information communication and knowledge synthesis and translation in the North; and support community-driven research projects.

The activities we undertook in order to address may of these goals included:

- **Delivering workshops**
  - health research ethics (Rankin Inlet, NU, November 2007)
  - Proposal writing (Cambridge Bay, NU, February 2008)
- **Holding a community consultation with participants from across Nunavut**

    - Rankin Inlet, NU (November 2007)
- **Giving presentations to partners and at conferences**
    - Pauktuutit Inuit Women's Association meeting: Sexual Health is Everyone's Responsibility (Inuvik, NT)
    - Inuit Tapiriit Kanatami (Ottawa, ON)
    - National Inuit Committee on Health (Iqaluit, NU)
    - Ajunnginiq Centre of National Aboriginal Health Organization (Ottawa, ON)
    - Nunavut Association of Municipalities Annual General Meeting (Iqaluit, NU)
    - Department of Health and Social Services (Iqaluit, NU and Cambridge Bay, NU)
    - Arctic Health Research Network – NWT Board Retreat (Shingle Point, NT)
    - Arctic Health Research Network – Yukon Health Promotion and Planning School (Whitehorse, YK)
- **Developing a quarterly newsletter**
- **Making improvements to our website**
- **Conducting community visits**
    - Cambridge Bay, NU (July, 2007 and February 2008)
    - Rankin Inlet, NU (July 2007 and November 2008)
- **Holding a Public Health Education Day**
    - Rankin Inlet, NU (November 2008)

This report outlines the achievements made in these areas during the past year at Qaujigiartiit/Arctic Health Research Network - Nunavut

Ethics

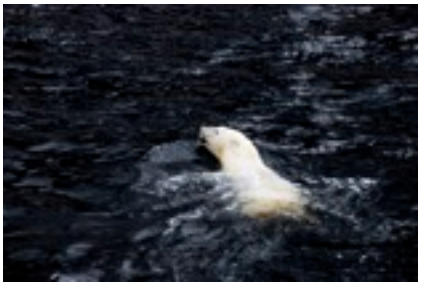
There exists a need throughout the Yukon, Northwest Territories and Nunavut to increase capacity to address issues of health research ethics, and in each territory the needs are diverse.

This desire to participate in health research underscores the need for community members to better understand and share their perspectives on health research ethics, and particularly CIHR's guidelines for the ethical conduct of health research in the North. It also highlights the need for the three territories to collaborate to address issues of capacity in ethical review of health research projects conducted in the North.

This final report outlines the year 1 activities conducted as part of a 3-year tri-territorial grant from the Tri-Territorial Health Access Fund (THAF).

It is our hope that the ideas discussed in this paper can be reviewed, discussed and individualized by communities, organizations and government so that we may work collaboratively to improve and support ethical review in the North.





Basic principles in health research ethics

The basic principles of ethical health research generally include autonomy, nonmaleficence, beneficence, and justice as touchstone principles for conducting ethical review of health research proposals (1).

Respect for autonomy is based on one's right to self-determination, which is generally implemented through 'informed consent'. Participants are seen as free-thinking individuals who must be informed about the purpose of the research, the possible harms and benefits associated with participating, processes to protect confidentiality and privacy, how the data will be used, participant rights and responsibilities, and withdrawal procedures should participants ever wish to withdraw. Once potential participants fully understand the scope and purpose of the research, they are considered enabled to make an "informed" decision about whether to participate.

Non maleficence (the principle of doing no harm) and beneficence (the obligation to do good) are operationalized through processes of "minimizing harm" and "maximizing good" in research. Research procedures that knowingly harm individual participants are always unacceptable.

Finally, the principle of justice means that all members of society should assume their fair share of both benefits and burdens of health research. It is unacceptable to coercively target vulnerable groups (e.g. children) or, without good reason, to ban a whole group (e.g. women) from studies that might benefit them. These principles maintain that morally acceptable ends and means should guide all research methodologies and processes.

Ethical dilemmas are a continuing problem in health research. Particularly, a focus on "individual ethics" has left some communities vulnerable to risks, for example, research conducted to advance academic careers at the expense of communities; wasting resources by selecting community-inappropriate methodologies; communities feeling over-researched, coerced or misled; researchers stigmatizing communities by releasing sensitive data without prior consultation; and communities feeling further marginalized by research (1). Finally, a particularly damaging effect of traditional research is that researchers often do not give back to communities. Most blatantly, findings are not shared with community members, and more commonly, researchers have done little to build capacity within communities.

The Arctic Health Research Network is playing a larger role in building community capacity for meaningful engagement with researchers coming to northern communities in an effort to change the power imbalance inherent in northern health research of the past. In addition, as is described in the following section, AHRN can play a role in the development, application and promotion of ethical guidelines for best practices in northern health research. It is our hope that the work conducted for this paper will provide the foundation upon which we continue to build ethics capacity in the North.

Goals of the AHRN Tri-territorial Ethics Project

Arctic Health Research Network (AHRN) in each territory has a mandate to serve as a resource centre for health research activities and to seek opportunities for educational partnerships in health research with a focus on Inuit, First Nations and other northerners' health issues.

As an organization designed to assist in the creation of community driven, northern lead, health and wellness research units, AHRN has a role to play in the development, application and promotion of ethical guidelines for best practices in northern health research.

The AHRN in each Territory is managed by a Board that is independent from the Boards in the other 2 territories, facilitating responsiveness to Territory-specific issues and priorities, including ethics. Communications are maintained between the three sites through regular communications between staff and an annual face to face meeting of Board Chairpersons and Executive Directors, contributing to the development of pan-Territorial outcomes such as this report.

To address these mandates, literature reviews, community consultations and educational workshops are an imperative part of the process of gathering information on community needs and involving community members in issues of health research.

The goals of this project were to (See Appendix A):

1. Develop a tri-territorial strategy for ethical review of health research involving Indigenous peoples
    - created a tri-territorial Advisory Committee to guide Arctic Health Research Network's ethics-related projects

2. Conduct a survey of existing ethical guidelines and literature that are relevant to northern populations.

3. Evaluate community capacity to provide input on ethical review of health research projects by
    - generating discussion among community members and organizations about health research ethics and how to work together to address our capacity needs
    - conducting consultations on health research ethics and Inuit/community perspectives on what it means to be ethical in research

4. To develop a draft of a Health Research Ethics Checklist for community proposal reviewers.

5. To consult communities about health research priorities in each region.

Common Themes Across the Territories

Licensing

Yukon

From a Yukon Territorial government perspective, licensing of scientific research in the Yukon is legislated through the Yukon Scientists and Explorers Act, and is administered through the Heritage Branch of the Territorial Government's Department of Tourism and Culture (2).

There is no specific reference to health research in this Act. The Act includes conditions applicable to all licenses, requirements to comply with the license, handling of specimens, reference to regulations which may be developed, and the penalty for violating the provisions of the Act, which includes the possibility of a fine of $1000 or imprisonment of six months, or both fine and imprisonment.

The application for this research license includes the following elements for the description of the project:

- Title of project
- Confirmation of consultation with Yukon First Nation(s) in whose traditional territory the research will be conducted. Include individual(s) contacted and date of contact. Attach any letters of approval or support to the application.
- Location(s) of area(s) of study (include N.T.S. map references)
- Schedule and dates of field work.
- Purpose and objectives of research project
- Proposed research plan and methodology
- Significance of proposed project
- Relation of project to previous work or other work in progress.

- Expected completion date (i.e. date of final report)

In all cases, applications to conduct research on specific traditional Yukon First Nation lands are reviewed and approved or not by the appropriate First Nation Government or Governments.

In addition, the Whitehorse General Hospital (WGH) has an Ethics Committee for clinical research activities conducted at WGH. Their Vision is "To become the leader in healthcare ethics in the Yukon", and their Mission "recognizes and responds to issues which create ethical and moral dilemmas and promotes discussion of these through multi-disciplinary partnerships; and promotes an ethical work environment, which integrates ethical principles and values" (3).

The Terms of Reference, Principles, Values, and Research Protocol are available upon request.

Northwest Territories and Nunavut

The NWT and Nunavut share the same Scientists Act. The processes for licensing a research project are outlined in the Scientists Act in Nunavut and the Northwest Territories. In addition, in the NWT there is a hospital-based ethics committee and a college-based ethics committee specifically for the nursing program.

For licensing, researchers are required to fill out a license application and submit their proposal with a 1 page summary in the appropriate local language where they will be working to the territorial research institute. The intent at this point is to afford local stakeholders and community and territorial representatives with an opportunity to review and evaluate the proposed research study. After a defined period of time, feedback is collected and sent to the researcher at which point they are asked to make suggested changes to their plans or are granted a license by the Science Advisor to cabinet (typically, the Executive Director of the local research institute).

In all regions of the North, power relationships between Indigenous communities and scientists are played out in various contexts, from environmental management, to land claims, to health research. Gearhard & Shirley (2007) argue that the research licensing consultation process under the Scientists Act in Nunavut has emerged as an important forum for negotiating power relationships between communities, scientists, and regulatory agencies in Nunavut (4). However, the authors highlight, communities and researchers alike are often unclear about what it entails, and in particular, about the role community agencies play in the license application review and approval process. Local reviewer feedback helps to inform the Science Advisor about community concerns and potential risks/benefits of each proposed project, but the final decision to approve or reject a license application or set the terms and conditions included in the license ultimately rests with the Science Advisor alone.

The Scientists Act suggests that research license applications may only be denied when the Science Advisor determines that the research will result in negative social or environmental impacts. The failure of a project to provide some desired socioeconomic benefits is not sufficient grounds for withholding a license, according to the current interpretation of the Act. Licenses may only be withheld when the Science Advisor decides there is documented, legally defensible evidence that the proposed project would have negative effects on the well-being of people or the environment. However, the Act does not make it clear how local concerns

are to be written/worded or proven in order to satisfy the Science Advisor that a license should not be issued. The Research Institutes makes every effort to facilitate communication between researchers and communities aimed at resolving disputes and reaching a mutually acceptable compromise over proposed research.

Clarifying research policies is one step to improving relations between scientists and communities. In addition, steps need to be taken at both policy and project levels to train researchers, educate funding programs, mobilize institutions, and empower communities, thereby strengthening the capacity of all stakeholders in northern research (4).

Principles of Respect

In terms of ethical health research in the North, it is important that it:

- Be based on trust, traditional values, respect, honor, honesty,
- Take a holistic approach to health, where the whole person is considered in the maintenance of wellness and treatment;
- Be connected to the mental, physical, spiritual, emotional and social aspects of health and well being of individuals and communities;
- Consider factors such as the impacts of housing, economy, education and culture, food insecurity;
- Take a broader inter-relationship approach to treating a person or maintain health and of the whole family, community
- Be respectful that Knowledge is historically passed down by generations through stories, songs and traditional practices.


Meaningful Engagement

From a Yukon First Nations' perspective, ethics and meaningful engagement in activities related to their health and well-being are inherently linked to the settlement of specific land claims:

> *Land Claims are commonly thought to have started in 1973 with the presentation of Together Today for Our Children Tomorrow to Prime Minister Pierre Trudeau in Ottawa by Elijah Smith and a delegation of the Yukon Chiefs. However, Yukon claims had been put forward as early as 1901 and 1902 when Chief Jim Boss of the present-day Ta'an Kwach'an and surrounding area, wrote letters to the Superintendent General of Indian Affairs in Ottawa and to the Commissioner of the Yukon. Jim Boss clearly outlined the concerns being felt by many of his people in terms of the alienation of lands and resources in their traditional areas and their need to have a say in*

their own affairs and governance. So it is clear that prior to 1973 Yukon First Nations have had long outstanding claims dating back to the time when some of the early effects of the Klondike Gold Rush and development in the Yukon were first being experienced by Yukon First Nations people.

- Council of Yukon First Nations (5)

In recent years First Nations in Canada have been engaged in developing their own research protocols, including in the Yukon. The Yukon First Nations (YFN) Heritage Group has developed a backgrounder to help First Nations communities (both self governing and non-claim settled) develop their own unique traditional knowledge polices, particularly as they relate to traditional ecological knowledge. The major points of the traditional knowledge policy framework are to be a guiding tool to assist First Nations in developing their own policies. For this reason, traditional knowledge and intellectual property rights in relation to research in the Yukon are controlled by each First Nation Government, in their development and implementation of protocols.

In Nunavut, participants in community consultations held over the years have indicated very strongly that Nunavut communities continue to be 'researched' without appropriate consultation. They also indicated that it is in the researchers' best interests to consult, as they will obtain more complete and accurate pictures of the phenomenon being studied.

In terms of how consultation plays a role in ethics, (6) propose that there are ethical goals in mind when a community is consulted:

- Enhanced Protection (of the community): Consultation may be a particularly effective way for investigators to work with community members to identify individuals or subgroups with particular needs or vulnerabilities that individuals outside the community may not recognize.
- Enhanced Benefits (for both): Communities should be involved in identifying research questions and planning studies in order to conduct studies that benefit the particular communities involved. Enhancing the benefits to ensure that research is mutually beneficial, for example – the community can advocate for additional services or training as part of engaging with the researchers.
- Legitimacy (of the research): By working in partnership, a forum will emerge in which community advisory members may discuss their views and concerns openly with researchers.
- Shared responsibility (community-researcher): Community advisory committees can be involved in recruitment, endorsement, dissemination and raising awareness. Sharing of responsibility does not constitute the shifting of blame or removal of responsibility from investigators, sponsors or institutional review boards. The degree to which responsibility can be shared is limited by the degree to which investigators and sponsors are sensitive to and accommodate those concerns.

Appropriate research methods

Health research methods are many and varied. Epidemiological methods, statistical research, qualitative and quantitative methods, and community-based participatory research. Each methodology helps answer specific questions. Participatory Action Research (PAR) and Community-based Participatory Research (CBPR) are two research paradigms that have come about as a way to address the ethical concerns of communities that have experienced "helicopter" research in the past. In the past, researchers frequently had exclusive control of the research process and use of the results. Participatory research attempts to break down the distinction between researcher and subjects and to build collaboration between the parties (7). Participatory research usually defines a research inquiry which involves: 1) some form of collaboration between the researchers and the researched; 2) a reciprocal process in which both parties educate one another; and 3) a focus on the production of local knowledge to improve interventions or professional practices.

Community-based participatory research is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities (Kellogg Foundation Community Health Scholars Program, 1). The process of community-based identification of issues of importance for research can be time consuming and labor intensive. In the North, the distances between communities and the many pressing issues facing communities pose challenges to this essential first step of CBPR.

Although sensitivity to vulnerable participants is integral in CBPR, a different set of ethical issues may emerge that require consideration (Flicker), such as:

- Community conflict: It is often difficult to find appropriate "community representatives" who will advocate on behalf of general community concerns. Sometimes it may be important to obtain consent at a community level from respected or elected leaders. This may cause conflict when community leaders and members disagree on the importance of a research issue.
- Compensation: Given the time and effort expended by community members on CBPR teams, there may be an ethical imperative to ensure that adequate compensation exists for all team members. Unfortunately, little or no incentives are provided to either the individual respondent or community representatives (e.g. the host organization or health centre) to acknowledge the time contributed to a project. This further disempowers individuals and communities by suggesting their time, energy, and resources may be of little worth, and they should participate simply because they have been invited.
- Sensitive Information: Ethical issues may arise in regards to releasing or disseminating sensitive or unflattering data. Academic partners may feel the need to publish and stay true to the "objective" nature of the data. Community members may fear that unflattering data may stigmatize their communities. Consequently, they may request that researchers consider the potential repercussions to the community if the data are released prematurely or in an insensitive manner.

These issues can potentially be addressed through a community research agreement, as discussed in Section 5 of this report.

While community-based research methods are promoted for research where the community is involved, research ethics boards do not take into consideration important aspects of this methodology when assessing proposed projects. In a review of forms and guidelines from American and Canadian research ethics boards at institutions with a public health program, Flicker, et al., (2007) found that a great proportion of the guidelines did not include evaluation of important components of a community-based participatory research project. For example, none (n = 30) queried community involvement in defining the research problem, asked about hiring practices, or examined what community capacity building opportunities there might be throughout the research process. Only one institution asked how unflattering data might be handled, but this had more to do with adverse events in medical research than the potentially stigmatizing results of socio-behavioural research. Only 5 institutions asked about plans for disseminating the results, and of those, none asked about procedures for terminating a study or vetoing publication based on community concerns. This is very important consideration for community-based research in the territories, as the licensing process in each territory is completely dependent upon ethical review conducted at the researcher's academic institution.

Finally, while community-based research methods have emerged as an important way to address ethical concerns of communities, they are not always an appropriate method. Other research methods are equally important when they are addressing community-led research questions or when communities are provided with an option to proceed with a community-based research approach or not, as articulated in the CIHR Guidelines (9).

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Ownership, Control, Access and Possession (OCAP) of data

The principles of OCAP (Ownership, Control, Access and Possession) are important to the ethical conduct of research involving northerners and northern Indigenous peoples. These principles have been advanced through the Assembly of First Nations (8), the National Aboriginal Health Organization and others.

The OCAP principles were adopted by the Council of Yukon First Nations Chiefs Leadership resolution (LDR Resolution NO782./06) passed in October 2006 which stated the following:

- OCAP protects communities from researchers coming in and leaving with data without sharing the information;
- OCAP protects the First Nations from conclusions that are reached without consideration on all the context or input from First Nations;
- OCAP enables First Nations partners and experts;
- In the past, researchers have treated First Nations as only a source of data;
- Research has been damaging in the past in instances where genetic material was used, sensitive information was published and confidential cultural information was shared inappropriately;
- OCAP will enhance Yukon First Nations control and capacity and lead to more useful and reliable information that will benefit Yukon First Nation communities, enable more informed decisions and create better results;
- OCAP also enhances self-determination.

It is within the context of these principles that ethical research protocols have already been developed by some First Nations governments in Yukon, and that will guide the development and implementation of these agreements now and in the future.

Additionally, these protocols can include requirements for additional information and conditions. The researchers must:

- Address issues that are common to all Indigenous peoples such as ownership, consent, control, access and protection of information and samples
- Outline how the project will directly benefit the community
- Have a detailed communications strategy
- Identify what infrastructure will be required
- Identify who will own the data and where it will be stored
- Identify if there will there be capacity building/training involved
- Identify if there will be economic benefits for the community
- Identify if there will there be samples of species taken, what will be done with them
- Follow Traditional Knowledge protocols for Indigenous peoples
- Include a list of partners and agencies involved
- Identify what the final product will be, and that it will be in a format useful to the community
- Includes knowledge of the people in the Traditional Territory/region/land area in a respected way.

Many of these conditions can be outlined in a community-researcher research agreement. For a community-based participatory research project in Kahnawahke, Macaulay, A.C., et al, (7) developed a 7-page 'code of ethics' document, or research agreement, that included a policy statement; principles of participatory research; the different between community-based and academic researchers; the obligations of researchers and the community; data ownership; the process of incorporating new investigators; and the procedure for joint dissemination of results including dissension if necessary. Inevitably, the nature of relationships and questions of ownership are complex factors that must be negotiated in each setting as need arises.

Sharing knowledge and communicating results

Results should be returned to the community in a format that is useful and understandable, such as through community radio, through community presentations, posters and informative pamphlets if appropriate, holding open forums and presentations in the community and/or visiting and speaking in schools, etc.

Sometimes researchers have published without consulting the community, resulting in negative consequences from publications where communities had no opportunity to correct misinformation or to challenge interpretations. Macaulay, et al. (7), included a statement in their community-researcher code of ethics that read:

> *"No partner can veto a communication. In the case of disagreement, the partner who disagrees must be invited to communicate their own interpretation of the data as an addition to the main communication, be it oral or written. All partners agree to withhold information if the alternative interpretation cannot be added and distributed at the same time, providing the disagreeing partners do not unduly delay the distribution process."*
>
> Macaulay A., et al, (7)

This type of agreement may be a way forward in dealing with such issues and encouraging the sharing of information, provided all parties agree to it.

Forming a Tri-territorial Ethics Advisory Committee

The projects outlined in this report were guided by a tri-territorial advisory committee that was formed by the Arctic Health Research Network. The Committee has 8 representatives: 2 from each territory and 2 national representatives who have worked in the field of health research ethics in Canada's North.

The committee discussed issues related to

- health research ethics review in the North;
- community-research agreements;
- were invited to review the health research ethics checklist for community proposal reviewers;
- shared literature, perspectives, experiences and expertise pertinent to health research ethics review in the North

This committee met primarily by teleconference and email, with plans for a face-to-face meeting for the following fiscal year.

A list of the members of this committee and the Terms of Reference are provided in Appendix A and B.

Reviewing community, territorial and national guidelines and literature for ethical conduct of health research

A number of guidelines, articles, and reports were gathered from communities, territorial and national organizations and other sources to assess what resources are available for communities. A list of the literature consulted for this report is listed with the reference section of this document.

Developing a health research ethics checklist for community proposal reviewers

The development of this tool was undertaken at the request of several community-based health research ethics proposal reviewers in Nunavut. The checklist is meant to be a guide in assisting community proposal reviewers to assess the ethical content of any health research project that is proposed to take place in their community. The checklist includes important questions about:

- community consultation and engagement in the research project
- assessing risks and benefits to the community/individual
- community research agreements
- sharing knowledge gained (dissemination) at the end of the project
- research methods
- confidentiality
- conflicts of interest
- advertisements and recruitment
- participant withdrawal
- financial or other compensation
- consent forms
- scientific review
- other comments

The checklist can also be helpful to those engaging in research review at the territorial level. The checklist has been reviewed by stakeholders in Nunavut; the AHRN Ethics Advisory Committee; the Inuit Health Research and Planning Winter Institute students (CIET Canada); and others. A draft of this checklist is provided in Appendix D.

Reviewing community-researcher research agreements in the territories

It has become a common practice for researchers to engage a community in a research project through a community-researcher research agreement. These contracts outline the responsibilities of the community member(s) involved and the researcher for the duration of the study period. They are signed by both a community member and by the researcher.

A template for a research agreement is available as an appendix in the CIHR Guidelines for the Conduct of Research with Aboriginal Peoples (9), developed by the Centre for Inuit Health and the Environment (CINE) at McGill University. Some communities have developed their own agreements/contracts for researchers, or researchers have developed innovative 'codes of ethics' in partnership with a community (7).

This topic is discussed further, below, in the section titled "Exploring Regional Capacity in the NWT", however, it requires further exploration across the territories to investigate such issues as local power dynamics; who speaks for the community when negotiating such agreements; how research agreements can be developed; and others.

Gathering Inuit and community perspectives on ethics

As described in an earlier section, the licensing process in Nunavut is the singular process or reviewing and providing feedback on health research projects, unless the researcher conducts consultations with the community in advance. The license is reviewed by Nunavut Tunngavik Inc., the Research Committee of the Dept. of Health and Social Services, the municipal council of the community involved, and other stakeholders as the topic requires. One of the concerns related to this process is that very often community members or the local municipal council either do not have adequate resources to evaluate the license or the time to do so given other obligations. In addition, due to the high turnover of staff in Nunavut, there are not always enough human resources at the various government and territorial organizations to ensure timely and thorough review of licensing applications.

Nunavut Ethics Workshop

Before the release of the CIHR Guidelines for the Conduct of Health Research with Aboriginal Peoples (9), the document underwent widespread consultation across Canada. Agencies in every Canadian province and territory were consulted about the document – except for Nunavut. In order to engage in a dialogue on ethical health research practices on more even footing, it was imperative that community members be invited to have their say on ethical conduct of health research in Nunavut. Evaluating capacity in Nunavut begins with discussions on what it means to be ethical from an Inuit and community perspective. For this reason, Qaujigiartiit/AHRN-Nunavut has conducted two consultations on health research ethics: 1) in Iqaluit, NU in 2006 on the CIHR Guidelines for the Conduct of Health Research with Aboriginal Peoples and 2) in Rankin Inlet, NU in 2007 to continue the dialogue on Inuit and community perspectives on health research ethics (14-16). Information from this meeting in provided in Appendix C.

The perspectives shared at these meetings primarily related to community values and respecting their role in ethics evaluation. Participants felt that it was unethical for researchers to not make efforts to build trusting relationships with community members and/or to reduce the power differential between researchers and community members through training, dialogue and other means.

Participants at our workshop highlighted several important themes in community-based research they felt were not only methodological considerations that they would like to see enhanced, but ethical considerations from the perspective of the community:

- Respect for the community
- Trust and building relationships
- Use of appropriate research methods
- Equality, equity and power
- Ownership of data (including samples)

- Sharing of knowledge gained from research
- Information about research processes

These feelings underscore a comment made by Martha Flaherty (past President, Pauktuutit Inuit Women's Association) at a workshop in Inuvik in 1995 held to bring researchers, organizations and community representatives together to discuss issues of health research ethics:

> *"Real participatory research must include Inuit control over the identification of areas and issues where research is needed and the design and delivery of the methodology. Inuit would participate in the collection and analysis of data and have equal control over the dissemination of the information and research findings. In my view,*



> *anything less is not participatory and it is unfair to call it such."*
>
> - Martha Flaherty, 1995 (10)

During discussions, 'Inuit ethics' were discussed by our participants and it is important to note that participants requested more dialogue with elders in future discussions about ethics in Nunavut, which Qaujigiartiit/ AHRN-NU will make every effort to support.

Research, Respect and Building Capacity: Negotiating relationships and working together

Participants in the Nunavut workshops highlighted the importance of respect and partnership between researchers and communities in northern research. They felt that spending time to develop relationships relieves stress for both researchers and community and creates a pleasant environment in which to work.

Participants made suggestions they felt would help facilitate a participatory process:

- consulting community members, especially elders, in addition to community leaders
- researching a topic of importance to the community
- including community members in the conduct of the research by hiring local knowledge holders or training local research assistants
- providing local training opportunities when appropriate

They also highlighted that communities need to be more aware of their rights to make requests of researchers and negotiate the terms of the research being conducted in their community. Participants noted that by working in partnership, researchers and community members can get to know each other, share worldviews and exchange knowledge in a meaningful and respectful way.

Improving participatory relationships has also been discussed quite extensively in the literature (1-7, 9-13)). Kaufert et al, (10) describe discussions at a meeting in Inuvik in 1995 where the members of the research community and members of the Canadian Indigenous community met to discuss health research ethics and communities. At this meeting, all parties agreed to focus on the importance of developing a more participatory process and that both sides would work together to:

- define research problems and obtain funding
- train and involve community members in data collection
- ensure the participation of community members and organizations in the analysis and interpretation of research findings
- develop joint control over the dissemination of results

Since that time, some progress has been made, particularly with the publication of the CIHR Guidelines for the Conduct of Health Research With Aboriginal Peoples (9), which are quickly becoming the gold standard guiding document. In addition, the Nunavut Research Institute and Inuit Tapiriit Kanatami have recently revised and published a document entitled *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers* (17). This progress is exciting and encouraging, and we hope to foster its continuation.

Information about research processes

Participants in the Nunavut workshops indicated that community members need more information about the research process in Nunavut, including how projects are licensed; who in the communities and territory are consulted during the development of the research project and during licensing; and how to increase community involvement in the research process from start to finish.

In order to continue to build capacity for ethical review in Nunavut, communities need to be well informed of their rights, their opportunities to have input on projects proposed to take place in their communities, and key ethical considerations for the conduct of research in their communities. While there has been some discussion within AHRN's consultations of the development of a northern-based ethical review board, it has become clear that while there is tremendous ability to provide ethical review, there is a dearth of capacity (in the form of community health committees, staff and staff time, small populations, previous engagement with research projects) to support such a board from Nunavut at this time. It is hoped, however, that this will improve over time with increased opportunities to build northern capacity for ethical review, including those provided by Qaujigiartiit/Arctic Health Research Network - Nunavut.

Recommendations for ethical review

The responsibility for ethical review in health research is usually assigned to university-based human subjects committees. As noted earlier, this is particularly the case in the North, as an ethical review is not conducted in any of the three territories – the licensing process, described earlier, is completely dependent upon university-based ethical review boards. The university-based committees usually do not have first-hand knowledge of local conditions, local needs or priorities, which can reduce the effectiveness of their review in a northern context. It has been noted in the literature (1,10) that central scientific and ethical review processes have limited capacity to assess potential local relevance of the research product. It has been proposed

that the central criteria for assessing the distribution of risks and benefits should be "whose interest does the research serve" (10. A concern in relation to reliance on non-northern-based ethical review committees (REBs) was their lack of local knowledge base, which limited their capacity to judge whether the process used to obtain community consent and participation was meaningful in local terms (10).

Given the information gathered from the literature, and experiences gathered from consultations within the Arctic Health Research Network in the 3 territories, recommendations for the content of ethical review include:

- Community-based Participatory Research Training
- Documentation of Processes
- Nature of Informed Consent
- Community Consultation
- Research Agreements

There is currently no ethical review process based in the three territories, therefore these recommendations are for institutions involved in ethical review of research in the North, and to be considered when a research ethics review board is developed in the North.

CBPR Training

Research Ethics Boards engaged in reviewing Community-based Participatory Research (CBPR), and other community-based research proposals, should be provided with basic training in the principles of CBPR (1).

Documentation of Processes

Research Ethics Boards should require CBPR projects to document the process by which key decisions regarding research design were made and how communities most affected were consulted (1).

Nature of Informed Consent

Research Ethics Boards should consider the nature of the community involved in the research project and whether the method of consent (language, written vs. oral, etc.) is appropriate. It has been suggested that if participants are to have access to full information, then all objectives and options, including non-participation, "had to be presented in an accessible format; including oral presentation in community forums, videotapes and documentation printed in Aboriginal languages" (10). The requirements for valid consent agreements usually include: (a) demonstration of subject competence; (b) communication of full information on risks and benefits; (c) assurance that the subject comprehended the information; (d) guarantees that the individual is able to act independently (Freeman, 1994, cited in Flicker, 2007). Consent agreements may need to use alternative media formats including video clips, community meetings, and community radio.

Community Consultation

Research Ethics Boards should consider the amount of time that has been spent consulting with the community, and if the partnerships formed are meaningful, i.e. described in detail in the context of the community and its leadership.

Research Agreements

Research Ethics Boards should mandate that CBPR projects seeking ethical review provide signed terms of reference, memoranda of understanding, and/or community research agreements. These should clearly outline the goals of the project, principles of partnership with the community, decision-making processes, roles and responsibilities of partners, and guidelines for how partnership will handle and disseminate data. (1)

Finally, Ruttan's statement (2004) articulates the findings of the Arctic Health Research Network in that:

> *An ethic based in mutual respect, reciprocal collaborative exchange, and an awareness of the personal, political and cultural consequences, particularly in light of past relationships, should guide our actions.*
>
> - Ruttan, 2004 (11)

The discussion of community ethics and ethical review will be on-going and continue within the work of the Arctic Health Research Network.

Knowledge Sharing

What is knowledge sharing?

Commonly, the concept of knowledge translation has been developed to refer to the creation and implementation of a strategy to translate health research results into applicable findings for those requiring the information. It has evolved conceptually as a means for bridging the "know-do" gap.

In the context of Qaujigiartiit/AHRN-NU and the work that is conducted by this organization, Knowledge Sharing is defined as

> *the synthesis, translation and communication of health knowledge between various knowledge holders, such as policy-and decision-makers; researchers; community members; and health care providers. Knowledge is dynamic and does not flow in a line from top to bottom, but fluidly between people and groups.*

Literature review

Methods

This literature review includes:

- A review of academic literature. The search was conducted by Janice Linton at the Health Sciences Library at the University of Manitoba. The initial scan of literature was conducted by Gwen Healey (Exec. Dir. Of Qaujigiartiit) and relevant articles were then requested and shipped to Nunavut for review by Mandie BzDell (Research Assistant at Qaujigiartiit).
- A review of grey literature (reports, conference proceedings, etc.) found on Google and on Google Scholar.
- Findings were read and summarized and are shared in this report.

Findings

Throughout the review, a number of findings relevant to knowledge sharing in Nunavut were highlighted and are presented below. These topics include:

- The need for clearer terminology
- The importance of frameworks
- Knowledge mapping as a conceptual framework fro knowledge sharing
- Knowledge sharing and Inuit community members
- Knowledge sharing and policy- and decision-makers
- Knowledge sharing and health care providers

- Knowledge sharing and researchers

These topics are further elaborated below in bullet-point form. A more in-depth presentation of these findings is available in our final report.

The Need for Clearer Terminology

- Synonyms for knowledge translation include knowledge translation, knowledge utilization, knowledge exchange, research transfer, research utilization
- It is important to have clear terms in order to evaluate effectiveness of knowledge translation

The Importance of Frameworks

- There is no primary knowledge translation theory – there are several different theories.
- One unified theory is required in the knowledge translation field in order to develop testable and probably useful interventions.
- Logan & Graham's Ottawa Model of Research Use – was the most favoured in the literature.
- All frameworks emphasize involvement of all stakeholders, and multi-directional flow of information.

Knowledge Mapping as a Conceptual Model for Knowledge Sharing

Knowledge mapping:

- Makes tacit and explicit knowledge concrete.
- May increase involvement of key stakeholders.
- Can assist in clarifying the flow of information.
- Can be used with all types of knowledge translation.

Knowledge Sharing and Inuit Community Members

- When conducting health research:
  - Community members involvement from deciding the research design to disseminating results is essential.
  - Community members have right to own research and negotiate community needs with researcher(s).
  - Community members may choose to establish an independent advisory and ethical review committee .
- In the context of health programming & services, the following Inuit-specific topics were discussed in the literature:
  - Face to face interactions are important for Inuit.
  - Storytelling is an integral part of Inuit health information dissemination
  - Elders are the preferred first line for health information in a number of communities and contexts.
  - Inuit see themselves as belonging to the larger Inuit community, irregardless of geography.
  - There is a shortage of interpreters who can translate health information.

Knowledge Sharing and Decision-Makers

- For decision-makers to apply research into daily decisions requires:
- A clear presentation of the evidence-based message.
- A credible source of research.
- Electronic, fast, staged access to information delivery of research message.
- Ongoing training for decision-makers on how to use research evidence in daily work is required for effective evidence-based decision-making.
- Information about evaluation of knowledge sharing activities is discussed in the literature.

Knowledge Sharing and Clinicians

- There exists too much research for clinicians to apply in practice.
- Knowledge translation is an important tool to close the gap between health evidence and clinical practice.
- Most effective strategies at getting clinicians to incorporate health research into practice are active, multiple, and based on accurate assessment of clinician needs.

Knowledge Sharing and Researchers

- When conducting research with community members in Inuit Regions:
  - Follow guidelines offered by CIHR "CIHR Guidelines for Health Research Involving Aboriginal Peoples" and by ITK & NRI "Negotiating Research Relationships with Inuit Communities: A Guide for Researchers"
  - Understand local processes of knowledge creation, dissemination, and utilization.
  - Use of community-based participatory research to make work responsive to the concerns of communities members.
  - Build research capacity within the community.
  - Use of an evaluator to do a variety of process evaluation through research process.
- When conducting research with decision-makers
  - Understand that knowledge translation must be interactive
  - Identify and understand the barriers for lack of use of research for decision-makers
  - Use interactive, non-passive forms of knowledge translation
- When conducting research with clinicians, it is helpful to consider:
  - It takes time to build trusting relationships and networks between researchers clinicians
  - The need to respect for clinicians priorities and interests
  - Recognition of clinicians' knowledge and expertise
  - The need for multi-directional information exchange and an ongoing forum for sharing including developing a shared language, culture, and conceptual base
  - The quality of in-person contact is important

Gaps in the Literature

Several gaps were identified during the literature review, such as:

- The need for truly community-driven research
- The need for evaluation of knowledge translation activities
- More information on the use of social network technology and its influence on knowledge sharing
- In the literature different users groups of health information are described, however, there is no information on the different literacy levels that are examined in these contexts, if any.



Community visits and sharing knowledge within Qaujigiartiit

Community Visits

For the Knowledge Sharing project, community visits were conducted in Rankin Inlet, NU and Cambridge Bay, NU. During these community visits, knowledge sharing was discussed and presentations and workshops were made to various stakeholder groups.

A workshop on proposal-writing was delivered to community members in Cambridge Bay, NU as a part of the discussions on knowledge sharing. This was done at the request of community members, and we were happy to be able to meet their needs.

A community visit to discuss sharing health information in Cambridge Bay also resulted in the development of a proposal for a community-driven health research project that was initiated and is being conducted by the local youth committee to explore issues of identity and suicide prevention for youth in the community.

In Rankin Inlet, a Public Health Education Day was held and a number of community members attended to learn more about community health and receive a flu shot. At this event, community members spoke openly to the attendees about the need for help addressing the issue of nutrition and food security in, not only this community, but across Nunavut. They highlighted that the extremely high cost of market foods was one of the primary influences of poor nutrition in the community.

Knowledge Sharing in Qaujigiartiit/AHRN-NU

Presentations

In the interests of sharing knowledge and improving communication between various agencies working in the North, presentations about Qaujigiartiit/AHRN-NU and the work being conducted by the organization were delivered to:

- Pauktuutit Inuit Women's Association meeting: Sexual Health is Everyone's Responsibility (Inuvik, NT)
- Inuit Tapiriit Kanatami (Ottawa, ON)
- National Inuit Committee on Health (Iqaluit, NU)
- Ajunnginiq Centre of National Aboriginal Health Organization (Ottawa, ON)
- Nunavut Association of Municipalities Annual General Meeting (Iqaluit, NU)
- Department of Health and Social Services (Iqaluit, NU and Cambridge Bay, NU)
- Arctic Health Research Network – NWT Board Retreat (Shingle Point, NT)
- Arctic Health Research Network – Yukon Health Promotion and Planning School (Whitehorse, YK)

Newsletter

In the last year, Qaujigiartiit/AHRN-NU began publishing a quarterly e-newsletter in English and Inuktitut to help facilitate the sharing of knowledge about Qaujigiartiit activities with community members and partners. Print copies are provided at conferences, community meetings and consultations.

Website – www.nunavut.arctichealth.ca

In consultations with both community and national partners, it becme apparent that several stakeholder groups were consulting the AHRN web site for information. In an effort to improve the sharing of information, Qaujigiartiit has undertaken revisions to the Arctic Health Research Network web site to facilitate the sharing of documents, community priorities for health research, information about scholarships and other important health news.

Teaching Resources

In addition, resources from Qaujigiartiit/AHRN-NU community consultations and projects were provided to educators, such as the CIET Inuit Winter Institute in Health Research Planning (Ottawa, ON February 2008) and other researchers who conduct work in Nunavut.

Community-driven Research Projects

The goals of community-driven research projects

Community-driven and -led research projects inherently designed to ensure that communities have an opportunity to answer their own health research questions, where possible; own the information; and hopefully apply the new information to policy and program development in the community.

Cambridge Bay youth exploring identity and suicide prevention through participatory video

The purpose of this project is to facilitate the exploration of culture and identity by and of youth in Cambridge Bay, Nunavut in relation to suicide through participatory video.

This project was initiated by youth of Cambridge Bay, Nunavut. Qaujigiartiit/AHRN-NU is facilitating the development of the methods that will be followed the project, providing some of the technical equipment and expertise, as well as agreeing to administer the funds for the project.

This project will add to the body of knowledge about suicide among Inuit. Particularly it will add to knowledge about the age group that is most at risk of suicide in Nunavut (young people under 30). In addition, it will provide an outlet for youth to express their feelings and their stories about culture, identity and suicide through a contemporary medium – video.

This project will provide an opportunity for youth and elders in one Nunavut community to work together to address an important health issue in the community. Resources will be developed through this project, such as a video dvd; a report; and a summary guide for other schools/youth groups to learn from the experience and conduct their own health projects.

Conclusion

Ethics

In order to continue to build capacity for ethical review in Nunavut, communities need to be well informed of their rights, their opportunities to have input on projects proposed to take place in their communities, and key ethical considerations for the conduct of research in their communities. While there has been some discussion within AHRN's consultations of the development of a northern-based ethical review board, it has become clear that while there is tremendous ability to provide ethical review, there is a dearth of capacity (in the form of community health committees, staff and staff time, small populations, previous engagement with research projects) to support such a board from Nunavut at this time. It is hoped, however, that this will improve over time with increased opportunities to build northern capacity for ethical review, including those provided by Qaujigiartiit/Arctic Health Research Network - Nunavut.

Knowledge Sharing

We are changing the concept of knowledge translation to include a more holistic, and broader view of knowledge, knowledge holders and knowledge transmission within all levels of research and community. We hope to continue these efforts to ensure knowledge is shared, used in practice and for decision-making, and celebrated.

Next Year

In 2008-09 we plan to:

1) Undertake projects examining
- food security and healthy food choices in Nunavut
- youth mental health and wellness

2) Develop resources for
- community members who wish to be more engaged in ethical review
- those negotiating research relationships in their communities

3) Provide training in:
- health promotion for community members
- community health research assistants

4) Support community-driven health research projects in Nunavut.

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Appendix A – AHRN Tri-territorial Ethics Advisory Committee

Marilyn Van Bibber (Yukon Representative)
Chairperson
Inter Tribal Health Authority, Research Secretariat
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Christiane Boisjoly (Yukon Representative)
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Appendix B – Terms of Reference for AHRN Ethics Advisory Committee

Terms of Reference – AHRN Ethics Advisory Committee

1. Committee Name: Arctic Health Research Network Ethics Advisory Committee

2. Date Created: July 2007

3. Contact Information:

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4. Committee Members:

Representatives to the committee should have considerable knowledge in the field of ethics, particularly as relates to northern and/or indigenous peoples.

Representatives from:

Yukon –	Lori Duncan
	Marilyn Van Bibber
NWT -	Cindy Orlaw
	Jane Modeste
Nunavut -	Janet McGrath
	Gwen Healey
National -	Nancy Gibson
	Laura Arbour

5. Current Chair: Gwen Healey

6. Chair selection and Term:

7. Committee Goals:

AHRN Vision:

The Arctic Health Research Network is working towards having people and facilities in place in northern communities to facilitate and conduct community-driven health research and raise awareness about health and wellness.

Goal of Committee

Provide advice, capacity and support to the Arctic Health Research Network for the purposes of developing a tri-territory strategy for Ethical Review for health research involving northerners and northern Indigenous peoples.

8. Committee roles & responsibilities:

The committee will provide guidance to the Arctic Health Research Network initiatives undertaken within the scope of this project from 2007-2010 in the following ways:

Participation in teleconference calls to discuss different aspects of the projects. The conference calls will be held approximately once a month or as needed.

Attendance at one face-to-face meeting per year where progress made on the project will be presented and discussed in further detail.

Committee members may be called upon to review documents or materials produced via this project to provide input.

9. Communication

The Committee will meet in person once per year, if possible.

Meetings of the committee will primarily be conducted by monthly teleconference calls, or calls as needed.

The majority of correspondence between calls will be conducted by email.

The meetings will be coordinated by the AHRN Ethics Project Coordinator who will also provide notice to the Committee of upcoming meetings.

Appendix C - Inuit and community perspectives on ethics in Nunavut

INUIT AND COMMUNITY PERSPECTIVES ON ETHICS AND HEALTH RESEARCH

Ethics

Participants were given a short presentation on ethics in research and learned about five principles of ethical research:

- beneficence (doing good, ensuring the research will have a benefit,
- non-maleficence (doing no harm)
- autonomy (the right to refuse participation)
- dignity (treating participants with dignity)
- truthfulness and honesty (about the nature of the research)

Participants also received short fact sheets developed by Qaujigiartiit/AHRN-NU on the CIHR Guidelines for the Conduct of Health Research with Aboriginal Peoples.

During discussions, 'Inuit ethics' were discussed by participants and it is important to note that participants requested more dialogue with elders in future discussions about ethics in Nunavut.

The information participants shared in this meeting will be used to inform the development of a Qaujigiartiit/AHRN-NU Ethics Checklist for communities to use when reviewing health research proposals.

Recommendations for researchers:

The participants at this workshop added the following recommendations for researchers coming to Nunavut:

- Researchers should consult with the community (about research questions, health topics, finding assistants, etc.), and especially elders when there is an opportunity
- Researchers should provide training opportunities when they are in communities, by:
  - Including community members in the research through consultation with local knowledge holders or hiring local research assistants
  - Holding open forums and presentations in the community and/or visiting and speaking in schools.
- Results should be returned to the community in a format that is useful and understandable, such as through community radio, through community presentations, posters and informative pamphlets if appropriate, etc..

Community Criteria for Research in Nunavut

Participants identified important criteria for what they would like see included as a part of their vision for health research in Nunavut.

Equality

- Community research assistants receiving credit for their contributions
- Equal treatment of researchers and community knowledge holders

Trust

- Consultation with communities before the start of projects

Results and knowledge sharing

- Research results shared with and presented back to community members in a format that is visible and understandable
- plain language reports;
- in-school presentations;
- talks on the radio, etc.

Ethics

- Territorial-level ethics review that incorporates Inuit ethics

Community comes first

- Researching a topic of importance to the community
- Community members conducting the research
- Researchers and community members sharing worldviews and getting to know each other
- Working in partnership with the community to relieve stress for both the researchers and the community

Participatory Action Research (PAR)

- Research method that promotes
- Equality in relationships
- The sharing of personal stories
- Pride in and ownership of what is learned/discovered

Appendix D – Community proposal reviewer checklist (Draft)

Reviewer Health Research Ethics Checklist

The purpose of this checklist is to provide a guide for the reviewer as to the kinds of ethical issues you should think about when reviewing a proposal for health research in Nunavut.

Community Engagement:

- ☐ Has there been any consultation with the community before the submission of the proposal? If so, what kind and with whom?
- ☐ Are there community partners (individuals, organizations, advisory groups, etc.)) involved in the project?
- ☐ Are community members involved in collecting information or guiding the project?
- ☐ How will community members be acknowledged for their contributions? Will it be in the form of publication credits, remuneration (payment), or some other way? Is this adequate/fair?

Community research agreement:

- ☐ Has a community research agreement been proposed? If so, who will represent the community to sign it?

Research Methods:

- ☐ Are research data management methods appropriate?
  - ☐ length of time
  - ☐ sensitive methodology
  - ☐ ensuring confidentiality
  - ☐ security and storage of files and data
  - ☐ data access issues once the study is complete

Risks and Benefits:

- ☐ Are there risks associated with this project? If so, are they clear? Do they effect a person or the community (or both or neither)?
- ☐ Are there benefits associated with this project? If so, are they clear?

Advertisements and Recruitment:

- ☐ Are there advertisements to recruit participants or advertise the study? Are they appropriate?

Confidentiality:

- ☐ Are the confidentiality protections appropriate? For example, what steps have they taken to make sure confidentiality will be maintained, and given the small populations of northern communities, are they adequate for the North?
- ☐ How do they propose to handle negative or sensitive results? Is this adequate/fair for the community?

Participant Withdrawal:

- ☐ Are there appropriate mechanisms for participants to withdraw from the study?

Financial or Other Compensation:

- ☐ Is there compensation to participants?
- ☐ Is it appropriate to their time and effort?
- ☐ Is it coercive (does it influence them to participate when normally they wouldn't)?
- ☐ Do they propose dollar amounts of compensation to participants? If so, is this acceptable?
- ☐ What is the funding source?
- ☐ Will the funding source want rights over data or publication?

Consent forms:

- ☐ Are they consistent with protocol?
- ☐ Is there a draft consent form submitted?
- ☐ Is the language (language and reading level) appropriate for participant population?
- ☐ Does it include a waiver of legal rights?
- ☐ Is the method of obtaining consent appropriate? Will it explained properly (i.e. by a person or through a video?)

Sharing Knowledge:

- ☐ Is there a clear explanation of how the research results will be shared with the community?
- ☐ Is it in a form that community members will understand?

Conflict of Interest:

- ☐ Are there any conflicts of interest (including with funders or with participants)?
- ☐ Have they been appropriately managed?

Scientific Review:

- ☐ Are the Hypothesis/research questions appropriate for the region?
- ☐ Are the recruitment/sampling strategies appropriate?
- ☐ Are the study numbers justified?

☐ Has there been a scientific review and/or ethical review by the proponent's university, organization, or any other northern body?

Any other reviewer comments:

Date & signature of primary reviewer